STRATEGY FOR IMPLEMENTING
ELECTRONIC ADVANCE DIRECTIVES
&
MOLST FORMS

An Information Brief

Health Information Exchange Challenge Grant

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MARYLAND HEALTH CARE COMMISSION

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Executive Summary

The Office of the National Coordinator for Health Information Technology awarded the Maryland Health Care Commission (MHCC) roughly $1.6 million in funding in 2011 to pilot the electronic exchange of clinical documents between paired long-term care facilities and hospitals through the statewide health information exchange (HIE). Funding for this pilot also calls for Maryland to plan and test the availability of electronic advance health care directives (advance directives) and Medical Orders for Life Sustaining Treatment (MOLST) forms. A focus group[1] was convened to deliberate on the technical and policy challenges related to electronic advance directives and MOLST forms. The focus group proposed the following recommendations:

1. **Enable advance directives to be electronic and accessible via a web portal.**

   Hospitals should be encouraged to include the ability for patients to upload and manage advance directives on their online patient portals so that such documents will be accessible to providers in their service area through the statewide HIE. Providers that have privileges in their community hospital should be able to access advance directive documents maintained by the hospital electronically through the statewide HIE. In the future, hospitals should make advance directive forms available to the statewide HIE for viewing by appropriately authorized and authenticated providers.

2. **Develop a database for electronic MOLST forms.**

   The statewide HIE should establish and maintain a tool for creating and storing electronic MOLST (eMOLST) forms. Providers required to generate a MOLST form upon discharge for defined populations should work towards electronically submitting this information to the statewide HIE. eMOLST forms would be made available by the statewide HIE to providers to view through the HIE's virtual health record.

Advance directives containing treatment preferences, also known as living wills, are created so that health care providers can administer care in accordance with the patient's wishes. These legal documents allow an individual to participate indirectly in future medical care decisions even if they become incapacitated. Enabling advance directives to be available electronically at the time and place of care could help ensure that a patient's wishes are known and honored. State law allows for the Maryland Department of Health & Mental Hygiene to establish an advance directives registry, subject to the availability of funds; funding is currently unavailable to support this initiative.[2]

In addition to advance directives, the MOLST form is a way of documenting a patient's treatment preferences. The MOLST form is a standardized medical order form that is valid across all health care facilities and replaces the Maryland Institute for Emergency Medical Services Systems *Do-Not-Resuscitate* form.[3] This form is a two page order form that informs providers what medical

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[1] Participants included representation from the Department of Health & Mental Hygiene; the Maryland Institute for Emergency Medical Services Systems; the AARP; the Health Facilities of Maryland; the emergency room physicians and Chief Information Officers of Maryland acute care hospitals; the Commission on Aging; the Hospice and Palliative Care Network of Maryland; MedChi, the State Medical Society; health systems; and long term care facilities.

[2] *Health - Advance Directives – Registry –Drivers' Licenses and Identification Cards,* Senate Bill 236 of 2006. Available online at: http://mlis.state.md.us/2006rs/bills/sb/sb0236e.pdf.

[3] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.

treatments a patient wants or does not want into orders that are valid across the continuum of care and reminds patients and providers of available options for end of life treatment. Twelve states have implemented and about 25 other states are developing a MOLST form. In 2011, the Maryland General Assembly enacted a law which requires long-term and post-acute care providers, as well as hospitals in certain situations, to create and maintain the MOLST form. Currently, this process is mostly manual and viewed as onerous by some providers. Health information technology provides an opportunity to simplify the process and promote access to electronic MOLST forms.

Report Limitations

The information contained in this document is limited to the contributions made by individuals participating in the focus group. A financial impact assessment and workflow analysis associated with implementing the recommendations was not included in the work effort. This information brief does not address costs associated with the statewide HIE, hospitals, or ambulatory physicians in adopting the recommendations.

Introduction

Advance directives allow an individual to appoint someone to make health care decisions in the event he or she becomes incapacitated, and permit health care providers to administer care in accordance with the patient's previously expressed wishes. Completion of Medical Power of Attorney and Living Will Forms promotes advance care planning. Enabling these documents to be available electronically as part of a patient's health record could help to ensure that advance directives are more readily available at the time and place of care.

Medical Orders for Life Sustaining Treatment (MOLST) forms allow a patient's preferences to be transformed into actionable medical orders. Patients with serious medical conditions, who want to avoid receiving any or all life-sustaining treatments, reside in long term care facilities and/or have a terminal illness, are generally the segments of the population that maintain MOLST forms. The completion of the form is based on a conversation between the patient, the patient's health care agent/power of attorney, and the provider, and ensures shared, informed medical decision-making.

Health information technology provides an opportunity to support the availability of these vital documents by enabling information to move electronically across unaffiliated facilities. Advance directives include information that is not necessarily included on the MOLST form, such as the individual the patient would like to make medical decisions on their behalf if they are no longer able to make their own decisions. The use of electronic advance directives and MOLST forms requires a commitment on the part of providers. The statewide health information exchange (HIE) will eventually offer a convenient method for accessing this information. A phased approach to implementing electronic advance directives and MOLST forms is required to ensure the eventual widespread electronic availability of this information.

Health Information Exchange

The statewide HIE can help to facilitate the availability of advance directives by enabling the electronic documents to be accessible through the statewide HIE. In general, HIE helps to deliver the right clinical information to the right place and time of care safely and securely. Maryland has made significant progress in establishing an infrastructure for statewide HIE. As of December 2011, 48 hospitals, including all 46 acute care hospitals in the state and two specialty hospitals, are sharing data with the statewide HIE. The statewide HIE plans to connect the more than 7,000 physician practices and 235 nursing homes in Maryland to enable information sharing. In 2011, the Maryland Health Care Commission (MHCC) received roughly $1.6 million in funding from the Office of the National Coordinator for Health Information Technology (ONC) to pilot the electronic exchange of clinical documents, between six pairs of long-term care facilities and geographically proximate hospitals through the statewide HIE, and develop the technology and policy framework for electronic advance directives.

Advance Directives and MOLST Forms – A Maryland Update

For many years stakeholders have been interested in increasing the availability of advance directives for Marylanders. During the 2005 legislative session of the Maryland General Assembly, House Bill 1004, *Public Power of Attorney – Health Care Decisions*, proposed the creation of a statewide registry for one type of advance directive, power of attorney for health care decision documents.[4] Though the bill did not pass, a comprehensive report on the possibility of a registry was developed, and in 2006 a statute was enacted directing the Department of Health and Mental Hygiene (DHMH) to build an advance directives registry, subject to the availability of funds. To date, funds have not been available to build the advance directives registry.

SB 236 enabled the adoption of regulation to ensure efficient operation of an advance directives registry. COMAR 10.23.01, *Advance Directive Registry*, describes the attributes of the planned registry. The regulation anticipates either a paper-based or electronic registry of all advance health care planning documents that will be accessible 24/7. The regulations stipulate a fee of $10, to be paid by the patient, provider or power of attorney, for each added or amended document logged to the registry. Included in the regulation are provisions for outreach and education to inform Marylanders of the registry and its benefits. The DHMH may provide for the registry either directly or on a contractual basis with a third party.[5]

MOLST forms are based on a patient's treatment preferences. A MOLST form is a medical order signed by a licensed physician or nurse practitioner. The MOLST form replaces the Maryland Institute for Emergency Medical Services Systems Do-Not-Resuscitate form, although existing EMS/DNR orders remain valid. The MOLST form will consolidate important information into orders that are valid across the continuum of care; standardize definitions and remind patients and providers of available treatment options; and increase the likelihood that a patient's wishes regarding life-sustaining treatments are honored throughout the health care system.

Concurrent to the development of COMAR 10.23.01, House Bill 82, *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form* (HB 82) was under development. HB 82 was signed into law during the 2011 General Assembly and requires the DHMH, the Maryland Institute for Emergency Medical Services Systems and the State Board of Physicians to develop a MOLST form and instructions for its completion and use.[6] Upon completion of the form, a copy must be given to the patient or authorized decision maker within 48 hours, or sooner if the patient is discharged or transferred. Beginning in 2012 (the exact timing has not yet been determined), health care organizations such as hospitals, nursing homes, hospices, and home health agencies will be required by law to complete or update a MOLST form for patients during a transition of care.

In the fall of 2011, the MHCC convened a multi-stakeholder advance directives focus group (focus group)[7] to evaluate the technology and policy challenges and propose solutions to enabling electronic advance directives and MOLST forms. The focus group agreed that a phased approach to

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[4] House Bill 1004, *Public Power of Attorney – Health Care Decisions*. Available at: http://mlis.state.md.us/google_docs$/2005rs/bills_noln/hb/fhb1004.pdf.
[5] COMAR 10.23.01, *Advance Directive Registry*. Available at: http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search=10.23.01.*.
[6] *Health Care Decisions Act – "Medical Orders for Life–Sustaining Treatment" Form*, House Bill 82. Available online at: http://mlis.state.md.us/2011rs/chapters_noln/Ch_434_hb0082E.pdf.
[7] For a list of focus group participants, see *Acknowledgements*.

broad exchange of advance directives is essential starting with hospitals and physicians, and that a centralized tool for MOLST forms would enable widespread adoption and use of these documents.

Advance Directive Initiatives in Other States

A small number of states have taken various approaches to making advance directives more readily available at the point of care. Some of these approaches are paper-based and, in the view of the focus group, not cost-effective or scalable. The focus group paid particular attention to the three identified states whose registries are tied to HIE initiatives: Oregon, New York and Virginia. Below are notable approaches from these states as it pertains to advance directives.

Oregon

Oregon has legislation similar to Maryland's MOLST law that has been in effect for several years. It is based on the Physicians Orders for Life Sustaining Treatment (POLST), which has since become a national initiative. In Oregon, emergency responders are trained to look for the brightly colored POLST form. Oregon decided to make the form bright pink so it would be easier to distinguish from white paper in an emergency. Patients are advised to keep their own copy of the POLST form in an accessible location; if it is not easily found, the registry serves as a backup. The registry was designed in 2008 and tested in 2009. Oregon regulations mandate that the physician who signs a POLST form send it to the registry unless a patient opts out of participation in the registry. As of March 2011, after about a year and a half of operation, about 50,000 POLST forms from are available in the registry.

New York

New York has also made progress on an electronic approach to advance directives. The state has a MOLST law similar to Maryland's. The HIE in Rochester has a patient portal; this is primarily because the HIE requires patients to opt-in to participate so that their data can be exchanged. The patient portal allows users to upload advance directives documents. This approach places the burden on the treating provider to interpret documents and determine the usability of documents. It is up to the patient to decide which documents to upload, and there is no independent validation or quality control. Also, proxies and caregivers may not upload or manage documents on behalf of others. Patient identity proofing poses a challenge. To date, use of the registry has been minimal.

Virginia

Virginia recently launched its own advance directives registry, overseen by the Virginia Department of Health. The registry is a secure website, hosted by a contractor based in Michigan, which allows any citizen of Virginia to create a free account and upload scanned care planning documents. Virginians can share access to these documents using a five-digit PIN of their choice. They can also print and carry a card which alerts others to the existence of documents in the registry. Currently, Virginia does not have a mechanism to validate the identity of any user of the registry. The state plans to connect the registry with the HIE sometime in the future.

Recommendations

The recommendations focus on the framework for storing and exchanging advance directives and MOLST forms electronically in Maryland through a phased approach to achieving wide-spread interoperability. The focus group identified a number of challenges associated with the current, paper-based paradigm for advance directives and MOLST forms, including: the likelihood of

disconnected care across multiple settings as patients travel between health care facilities, the paper-based nature of the process itself; the existence and dissemination of documents that are not up-to-date or may not reflect current wishes. The focus group sought to address as many of these challenges as possible in the recommendations.

1. **Enable advance directives to be electronic and accessible via a web portal.**

   Hospitals should be encouraged to include the ability for patients to upload and manage advance directives on their online patient portals so that such documents will be accessible to providers in their service area through the statewide HIE. Providers who have privileges in their community hospital should be able to access advance directive documents maintained by the hospital electronically through the statewide HIE. In the future, hospitals should make advance directive forms available to the statewide HIE for viewing by appropriately authorized and authenticated providers.

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The focus group generally agreed that advance directives and MOLST forms be available in a registry that can be accessed quickly to assist with health care decisions. However, the focus group discussed challenges with relying on the information provided from a registry to make treatment decisions. The focus group mostly felt an electronic registry is an improvement over what exists today, which is a manual system that has many inefficiencies. The focus group viewed a phased approach as a practical way to implement electronic advance directives and MOLST forms in Maryland that will enable stakeholders to share challenges and collaborate on solutions as technology is adopted. A voluntary adoption approach was preferred by the focus group. A strategy for engaging hospitals, physicians, and the statewide HIE will need to be developed. Evaluation of a voluntary approach is necessary to determine if potential legislation is required.

Remarks

Stakeholders agree that it is time to take advantage of technology to increase the use of advance directives and the MOLST form. Subtle disagreement exists in who should pay to implement the technology. Most hospitals are beginning to make clinical information available to physicians through a web portal. Nearly all physicians have access to a high speed Internet connection. The statewide HIE currently has a robust infrastructure that supports the exchange of electronic health information. A shared implementation approach among hospitals, physicians, and the statewide HIE is required to support the focus group recommendations. In general, with modest effort, existing technology can serve as the foundation to support electronic advance directives and the MOLST form. Most stakeholders suggest the benefits of implementing the technology outweighs the cost.

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